

ALS Care Options

Providing care for a person living with ALS can be challenging, especially as the disease progresses. Family caregivers often struggle to care for their loved one while juggling the demands of daily life.

Here are some options for finding additional care and support:

Home Health Services

These short-term skilled nursing and therapy services (physical, occupational, speech language) are prescribed by your neurologist when needed and should be covered by insurance as long as you have an ALS diagnosis, qualify for Medicare, use Medicare-certified home health agencies, and are certified as homebound by a doctor who regularly reviews your care plan. Home health services also include home assessments, training for caregivers (feeding tubes, transferring, etc.), social services like counseling, and some personal care services like bathing, toileting, and dressing (if these services facilitate skilled nursing care that is already in the home).

Home Care (non-medical)

Home care provides assistance with daily activities like bathing, toileting, dressing, and eating. It is not usually covered by insurance and can be expensive over time. Non-medical home care is provided in the home by paid caregivers who are either independent or employed by a home health care agency. It can provide much-needed breaks for primary family caregivers. When looking for non-medical home care, you'll need to decide whether you want to hire an independent caregiver or go through an agency with caregivers on staff.

Respite Care

Respite care is any type of short-term caregiving assistance that provides rest and relief for the primary caregiver (often a spouse, family member, or close friend). Respite care is not covered by insurance. Depending on your support network and the resources available in your area, you may be able to find respite care at no cost. **Some local ALS organizations have grants that pay professional caregivers to come to your home for a certain number of hours a month at no cost to you. Ask if there are any programs like this in your area.** You can also ask for help from your family, friends, and greater community. Respite care can help minimize exhaustion, depression, irritability, social withdrawal, and other effects of caregiver burnout. When caregivers have time for their own self-care, they are often better caregivers.

Palliative Care

Palliative care provides specialized medical care for anyone diagnosed with a serious illness. A medical team will work with you to manage pain and symptoms and improve your comfort level. Palliative care adds an additional layer to your current care. Your palliative doctor will coordinate your care with your neurologist and primary care doctor. A nurse and social worker will check on you periodically.

Hospice Care

Hospice is a service that provides compassionate care and comfort for terminally ill patients at the end of life. Most people receive hospice care at home, though it is also available in hospice centers, hospitals, nursing homes, and other long-term care facilities. The ultimate goal of hospice is to provide quality of life at the end of life. Insurance will cover hospice services at home. Each hospice provider is unique, but hospice care typically includes a care team led by a medical director, an individualized care plan, pain and symptom management, medications, medical supplies and related equipment, home visits by a nurse once a week, home visits by a nurse's aide a few times a week to assist with bathing and dressing, emotional and spiritual counseling for the patient and/or family, and bereavement support.

Veterans Affairs (VA)

The VA provides extensive service-connected benefits for U.S. military veterans diagnosed with ALS, including benefits for personal care.

Long-term Care Policies

If you purchased a long-term care policy prior to your symptoms and diagnosis—and have been paying your premiums—you should receive financial assistance to help pay for non-medical long-term care. If you have a long-term care provision or rider through your life insurance policy, you should also receive financial assistance with long-term care.

Get Local Support

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